

## **Danny Heumann's Testimony before the House Health Policy Committee on Embryonic Stem Cell Research and Somatic Cell Nuclear Transfer**

**March 21, 2005**

### **I. Introduction**

My name is Daniel Heumann; I'm a T-5 paraplegic. I'm the Vice President of the Daniel Heumann Fund for Spinal Cord Research. I drove here this morning from Ann Arbor, MI where I live with my wife Lynn and my 2 year old daughter Katie. I want to thank Chairman Gaffney and the members of this committee for organizing this hearing. It's an honor for me to be here this morning, so I can testify about cutting edge research that could possibly be the magic bullet to get me out of this wheelchair. I'm very happy that legislators from both sides of the aisle are beginning to realize the potential and promise of embryonic stem cell research. However, I echo the words of Christopher Reeve telling Congress when he testified a few years or so ago on this issue, how sad he was that research that could cure him was a political football being debated on the floors of the House and the Senate.

### **II. Background**

- A) I would like to share with you why I'm sitting in front of you today. After I graduated from High School in NYC, I got a job as a counselor at a summer camp in Upstate, NY. On the night of August 13<sup>th</sup>, 1985 at 11:29PM I walked into the backseat of a car where there were no drugs or alcohol involved. At 11:31PM I became a paraplegic. The driver of the car was speeding around a curve in the Adirondack Mountains. He was killed and the two other passengers walked away without a scratch. My accident happened two weeks before I was suppose to start my freshman year at Syracuse University.
- B) I'm 39 years old. More than ½ my life has been spent in a wheelchair as a T-5 paraplegic. Everyday when I open my eyes, I face a day with significant physical challenges. Many times I find myself soaked in my own urine because I no longer have proper bladder function. As a T-5 paraplegic, I'm paralyzed from the chest down, so sitting up in bed is very difficult since my stomach muscles no longer work. Furthermore, when I get up in the morning, my legs are stiff like cement bricks. Then, to move them off the bed so into my wheelchair takes tremendous

effort. Once I'm in my wheelchair, I'm faced with a 3-4 hour morning routine that includes going to the bathroom, showering, and dressing. My bowel routine alone can take up to 2 hours. I have to wear this glove and put this enema inside my rectum because it's paralyzed. Then I have to manually take my stool out of my rectum. To urinate, I have to use a catheter 8 to 10 times a day. As a result of my spinal cord injury, I'm very susceptible to pressure sores and infections. Currently, I have a pressure sore on the top of my right foot. Pressure sores are very dangerous – they occur within a few hours and take up to a year to heal. Christopher Reeve was suffering from a pressure sore and it played a large role in his death. Another common and dangerous issue that I've now had 3 times is cellulites. Unlike an able bodied person who would have pain as the cellulites take hold, I do not. Instead, it is often advanced and I don't know until I have a high fever and my white blood cell count is extremely elevated. I've been hospitalized for a week twice with this over the last three years.

- C) Despite all the problems associated with a spinal cord injury, I work very hard to live a fulfilling life. I started my own motivational speaking company. Through my company Heumannly Capable I speak to corporations, universities, high schools, at various conferences helping people live a fulfilling life. I also play wheelchair tennis and love beating my able-bodied opponents. As I mentioned earlier, I'm a husband and a father of 2 year old daughter who was conceived through IVF. If it was not for this medical technology I and millions of people in Michigan and around the world would not be parents today.

### **III. Stem Cell Research Advocate**

- A) After my accident, while I was in rehab, friends and family kept asking my parents what they could do to help. My parents and I decided to start the Daniel Heumann Fund for Spinal Cord Research. In 1986, when the DHF received its 501c3 status, there was little hope that a cure for paralysis could be found. There were few foundations funding spinal cord research. No pharmaceutical companies or biotechnology companies were giving any money for neuro protective drugs or innovations that would help the spinal cord regenerate. It was 9 1/2 years before Christopher Reeve had his accident. My parents were not celebrities like Christopher Reeve or Nick Buoniconti They were regular people who would not buy into the medical establishment's diagnosis that their son would spend the rest of his life in a wheelchair and never be able to biologically father his own child. To date the DHF has raised close to 5 million for spinal cord research

B) I became a patient Advocate for stem cell research in 2004 when I was asked by the Genetics Policy Institute to be there patient advocate speaker at the United Nations. After speaking at the UN, I came back to Michigan to learn we are one of the most restrictive States when it comes to this research. I shared these disturbing facts with Rep. Meisner and his staff, and that's why we are all here this morning.

#### **IV. Prospects for a Cure**

A) This is the first area of research where many disease advocacy groups are uniting and working together. Scientists now know the potential and promise of this research and it is time to allow this work to proceed in an ethical and moral manner. Working at our foundation has educated me and I believe that embryonic stem cell research is a very important piece of the puzzle. However, if scientists were allowed to do their job in this state without both arms tied behind their backs I repeat, embryonic stem cell research could very well be the magic bullet to get me out of this wheelchair, or to cure so many others who suffer. I am not just a person with a disability who is jumping on a bandwagon hoping for a cure. I have done the reading, spoken to scientists and advocates. This is not a pipedream – this could be the most important medical discovery of the 21<sup>st</sup> century. As Nancy Reagan said “We’ve lost so much time already and I just can’t bear to lose any more”

#### **V. the role of Bio-tech**

Last month I was featured in an article in the Detroit News “The Stem Cell Debate: Ethics verse New Jobs.” I was very upset with negative connotation of this headline. In my letter to the editor I pointed out that new jobs is a secondary issue concerning the important role the bio-tech plays in curing diseases and disabilities that afflict so many of our loved ones here in Michigan. The Bio-tech industry is responsible for getting the therapies/technologies out of the universities and into clinical trials. As somebody who is an investor in a bio-tech company, I know first-hand the risks a bio-tech company assumes when they pay a university millions of dollars to get a specific therapy/technology out of the lab and into the market place, with the hope that technology/therapy will receive FDA approval. In order for that technology/therapy to receive FDA approval, the bio-tech company usually has to create a three phase clinical trial, where more millions are spent, in the hope that the technology/therapy will produce the positive data needed for FDA approval. As a patient who suffers with a spinal cord injury, I appreciate the economic risks bio-tech companies take everyday to find cures for the patient populations they are trying to help. I want this committee to know that the bio-tech industry is about finding cures. New jobs are a by-product of a thriving bio-tech industry in states that have legislation allowing scientists to do cutting-edge research in an ethical moral manner.

## VI. What Rep Meisner's Legislation Means to Me

Two words immediately come to my mind when I think about Rep Meisner's legislation - **Freedom** and **Hope**. Giving scientists access to embryos that otherwise would be discarded will have an immediate positive impact on this research.

As a husband and father, Rep Meisner's legislation will open the door to me possibly doing things for my family that able-bodied husbands and fathers take for granted. I would like to have the ability to get on the floor with my daughter and not have to worry about struggling to get back in my wheelchair. I'd like to take a walk with her on the beach and hold her hand with both of us feeling the sand between our toes. I'd like to be able to help my wife with all the physical tasks that she has to do because of my paralysis. I'm tired of feeling like I'm burdening those who are close to me. I would like to be able to have normal sexual relations with my wife, so we wouldn't have to spend \$20,000.00 plus on IVF treatments, so my daughter might have a sibling.

In closing, millions of patients just like me are looking to our leaders in government to do everything they can to alleviate human suffering. Members of this committee, the hour is at hand that you can have a direct impact in advancing the greatest medical hope of our time. Please don't let us down.